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AUTHOR Toro-Alfonso, Jose
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ABSTRACT

The Colectivo de Concientizacion Gay, a homosexual and lesbian organization in Puerto Rico, developed a brief analysis of what has happened since symptoms associated with acquired immunodeficiency syndrome (AIDS) were first reported by the Centers for Disease Control in 1981; the analysis also included implications for the gay community. Since homosexuals were the first AIDS victims, the disease was linked to this way of life. The homosexualization of the disease had a negative influence on the handling of research, the assignment of funds, the treatment of patients, and the content of public information. AIDS, however, is a concern of general public health and is not exclusive to homosexuals. Statistics of the Latin American Center of Sexually Transmitted Diseases indicate that in Puerto Rico the major percentage of AIDS patients is not composed of homosexuals. Nonetheless, a homosexual stigma seems to predominate in communities. Homosexuals must maintain objectivity in dealing with AIDS. They must assume responsibility for taking precautions to avoid the contamination and transmission of the disease. For some this will mean low risk sexual behaviors, for others the alternative of monogamy. Homosexuals must beware of fostering social prejudice. It is difficult to determine where genuine concern ends and homophobia begins. (NB)

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AIDS: Implications for homosexual self-help and support efforts

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José Toro-Alfonso
Colectivo de Concientización Gay
Puerto Rico

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In 1981 the Center for Disease Control in Atlanta started to report the first cases of opportunistic infections and Karposi Sarcoma in previously healthy male homosexuals (López Malpica, 1983). These symptoms are generally associated with the Acquired Inmunodefienciency Syndrome known as AIDS. The *Colectivo de Concientización Gay*, a homosexual and lesbian organization in Puerto Rico, wanted to develop a brief analysis of what has happened since that summer of 1981 and its implications, particularly for the gay community. This paper represents only the *Colectivos'* point of view. This organization does not represent the entire gay community in Puerto Rico. In fact, this community is characterized by its heterogeneity and multiple perspectives regarding all issues. Thus this report is only this groups' analysis of the situation.

From February to December, 1983, 1,000 cases of AIDS had been reported in the U.S. which were distributed as follows: 75% among homosexuals, 14% among heroin drug users, and 6% in hemophiliacs. These cases were distributed in New York (51%), California (21%), Florida (7%) and the remaining 20% were found in other states and in Puerto Rico (AHA,1985; Mayer & Pizer, 1984). It is widely known that specifically, California and New York, contain the strongest organizations of homosexuals and lesbians in the U.S. Since 1969, an organized attempt to rescue the civil rights previously denied to homosexuals and lesbians was developed in these cities. Through this effort, a number of homosexuals developed a sense of community and a way of life that was previously unknown to the heterosexual society. Since homosexuals were the first AIDS victims, the disease was linked to this way of life. I was thus inferred that not only did homsexuals live differently, they also had their own particular illnesses

(Altman, 1985). For a while AIDS was commonly known as the "gay plague" and although this name was never officially accepted, it did penetrate attitudes and perceptions of the community as a whole which was alerted to the possible development of a new epidemic.

On the other hand, it was undeniable that the illness was causing a strong impact on the homosexual community and it was necessary to respond to that situation. Different groups under homosexual leadership were inmediately organized to raise funds for research, to develop educational programs and to offer help to patients. This fact, contradictorily, caused the continued association of the disease with homosexuality. For homosexuals it was the only alternative, either they gained command of the situation or no one would act. After all, homosexuals are the only ones within the known "high risk groups" that have the capacity to organize around this issue, different from drug addicts, hemophiliacs or bisexuals.

Thus we cannot ignore the negative influence of the homosexualization of the disease on the handling of research, the assignment of funds,the treatment of patients or the content of public information. In comparison we might recall the way that"legionnaires disease" and the intoxication syndrome attributed to tampons, were handled. These situations received prompt and adequate investigation and action. Our analysis also has to include the influence of the platforms of U.S. political parties with regards to homosexuality and how they delay the opportune assignement of funds for AIDS by Congress. This allotment of moneys would contradict party positions by tacitly endorsing homosexuality. This would be inadmisible for the Reagan administration and for groups that openly support it such as Moral Majority and Morality in Media.

It seems evident that the constant association between homosexuality and AIDS also has important repercussions on the way the disease is perceived. It was not until recently that the Puerto Rican Health Department revised its' education campaign regarding AIDS eliminating the term homosexual and substituting it with the phrase"people that have promiscuous sexul relations" when mentioning the "high risk groups" in their brochures and ads in newspapers.

With the information we have at the moment, it would not be repetitive to insist that the AIDS situation is one of general public health and that it is not an exclusive problem of homosexuals (Goldsmith, 1985). In Puerto Rico, especifically, the statistics of the Latinamerican Center of Sexually Transmitted Diseases (LCSTD) indicate that the major percentage of AIDS patients is not composed of homosexuals. According to their statistics, up to september of 1985, Puerto Rican victims include: non-addicted homosexuals (37.1%) and addicted homosexuals (7.1%) for a total of 44.2% and 55.8 % distributed among heterosexuals, bisexuals, hemophiliacs and others.

These statistics them make us think that it may be more the homosexual stigma, than the dread of a contagious and unknown disease, which predominates in all of the community when the topic is approached or studied, or when patients are treated. There have been many cases of patients verbalizing the difficulties they have experienced since their initial diagnosis (Daly, 1983). They have been rejected by their families, pressured to leave their jobs, stigmatized by medical personnel (Daly, 1985), abandoned to loneliness during their moments of death, and there has been resistance to provide them with the funeral services that they are entitled to (Dávila,

1985; Villegas, 1983).

Where does the fear of an unknown disease end and the homophobia of the parishioners of the catholiic dioceses of N.Y. begin, when they oppose the use of a building belonging to the church for the shelter of AIDS patients (Fuerbringer,1985a)? Where does the worry end and homophobia begin, when the U.S. Army questions the need to examine its recruits for antibodies of the disease (Fuerbringer, 1985b)? Where does the general public interest end and the homophobia begin, when the closing of homosexual bars and discotheques in San Francisco is chosen as the only alternative and the legislatures of different states in the U.S. are pressured to reject or ignore the different law projects in favor of the rights of homosexuals and lesbians? Definitely AIDS brings a sequel of implications for homosexuals and lesbians beyond medical and health issues. Let's examine some of them.

First, we should call attention to a hardly mentioned fact. Nothing has been said about lesbians and their relationship to the disease. When the term homosexual is used, theoretically it refers to male and female homosexuals. This means that when homosexuals are mentioned as a "high risk group" it should include lesbians. However, that mention does not take into account that lesbians are the group with the lowest risk of AIDS (Garib, 1985). We ask ourselves if this omission responds to the general tendency of society to deny the existence of lebians and their sexuality.

There is another implication of the way AIDS is dealt with which is of vital importance.This is the relationship[which is stated to exist between sex and death. We are not dealing with a traditional disease for which there is a cure, but with an illness for which there is no cure and is acquired through sexual contact. This link may lead to a revision of the attitudes that

initiated the first movements in favor of gay rights in Germany in 1929 and in N.Y. in 1969. These attitudes tried to challenge the bases of heterosexuality elaborating new forms of relationships and allowing for the free expression of homosexuality (Lauritsen and Thorstad, 1974). Could this mean the return to the "closet" and the disappearance of this freedom rescued by homosexuals and lesbians, or the obligation to return to closed relationships very similar to those that we have so strongly rejected?

Unquestionably the situation has created an awareness concerning health. The homosexual community has become aware of the need to be healthy, to minimize the use of stimulants such as alcohol and drugs, to guarantee a balanced diet and enough rest and above all, of the importance of establishing relationships which will guarantee health. However, the homosexual community should give thought to the fact that none has thought of giving away needles to addicts, nor has anyone thought of organizing massive campaigns in shopping centers to give away prophilatics without order or discretion. But people have thought of to demanding responsibility from the gay community by suggesting new standards for their sexual behavior, thus reinforcing the game of blaming the victim.

On the other hand it is important to point out that the epidemic has managed to reactivate the homosexuals' sense of community, particularly, in those countries which have strongly organized movements. In many places the initiative to organize around the needs that have appeared has been taken by homosexuals. We can mention the Gay Men's Health Crisis Center of N.Y., Los Angeles AIDS Project, Shanti Project and San Francisco AIDS Foundation among others. In addition we have the Rock Hudson Foundation which was organized recently, succesfully encouraged by a homosexual. In different

places support groups which devote themselves to visiting the sick, to take them to their medical appointments and to accompany them during death, have been organized. Without any doubt, the situation has required a new view of participation in community affairs.

In Puerto Rico the situation has been sligthly different because of the lack of groups with sufficient organizational capacity, because of the fragmentation of the homosexual community, and maybe, because many of the initial attempts to deal with AIDS were carried out by governmental organizations of which homosexuals regularly distrust. However, it would be unfair to omit that, in one way or another,homosexuals in P.R. have taken an active part in the development of different efforts that are being undertaken to fight the disease, even if it is on a personal basis and not necessarily as an openly identified homosexual. These efforts have taken place specially through organizations such as the AIDS Foundation of P.R., Inc. and the Institute for the Study of Inmunodeficiencies.

This may well prove to be significant since the disease may signify, slowly or abruptly coming out of the "closet" . For some this occurs because they are confronted with the disease as patients, for others because we confront the disease from a social perspective and as our duty. But, without a doubt, both positions require the public exposure of our sexual preference.

The work that different support groups are doing within the gay community in relation to the AIDS situation goes beyond merely managing all situations related to the medical issues. We are confronted with the elaboration of the best strategies to help patients deal with all the difficulties that a terminal illnes brings, with the hostile treatment of medical and para-medical staff, and with rejection and social stigma. But,

above all, we are confronted with the great difficulty of constantly dealing with the association of the epidemic to our particular sexual preference. We add on to this difficulty, within support groups, the need to create parallel processes that place within a fair perspective the daily relationship with the image of inevitable death; the wait for the feared news of an initial diagnosis and the canalization of diffuse anger that on many occassions is not adequately dealt with. The complexity of the situation requires the elaboration of a different concept of support groups beyond the previous styles. This time we are not dealing with groups developing awareness nor lobbying and exerting legislative pressure, but with the creation of groups dealing with a life or death situation.

Maybe one of the major implications that the development of these different groups may have is the fact that they assume, consciously or unconsciously, the States' responsibility for the procurement of health services in similar situations. Specifically, the support groups that develop have taken from governmental institutions the responsiblity to guarantee and provide health services without distinction to people. It was assumed, from the beginning, that a situation which affected a sector that is outcast by society would not receive attention by the governmental sectors in charge of health. but at the same time, these sectors and the community in general are under the wrong impression that in any situation related to AIDS the exclusive responsibility should rest on the homosexual community.

The groups led by homosexuals have received help from very few sources (Helquist, 1985). Just a few religious organizations with visions of magnanimity , based on the idea the "God hates sin but loves sinners" have begun to collaborate with the different support groups in the development of

small shelters for AIDS patients . One example is the congregation of nuns led by Mother Theresa of Calcutta.

Definitely there are many factors that we must take into account when we confront this epidemic. An attitude of utmost objectivity is fundamental . As members of a "high risk group" and within our support groups, we must take all the necessary precautions to responsibly avoid the contamination and transmission of the disease. For some this will mean low risk sexual behaviors, for others the alternative of monogamy. But all of us must beware of fostering social prejudice. Because, after all, it is always difficult to determine where genuine concern ends and homophobia begins.

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